Evaluating the transparency of pharmaceutical company disclosure of payments to patient organisations in the UK

Emily Rickard[1], Piotr Ozieranski[2], Shai Mulinari[3]

[1] – Department of Social and Policy Sciences, University of Bath, Claverton Down, Bath, UK; Doctoral Student
[2] – Department of Social and Policy Sciences, University of Bath, Claverton Down, Bath, UK; Lecturer
[3] – Department of Sociology, Lund University, Lund, Sweden; Associate Professor

Abstract

Patient organisations contribute to many areas of pharmaceutical policy. In developing their organisational capacity, many turn to financial support from pharmaceutical companies, which may create conflicts of interests. However, the transparency of the industry's self-regulatory approach to the disclosure of payments to patient organisations has evaded scrutiny. Using company reports disclosing payments to UK patient organisations in 2012-2016, we evaluate the transparency of reporting using indicators derived from industry's European patient organisation Code. We found a large proportion of companies did not have any disclosure reports available despite many having made payments, confirmed by comparing with annual financial accounts of patient organisations registered as charities. Where disclosure reports were available, many payments were not adequately described, resulting in large portions of money being disclosed without clarity as to the payment type and purpose. We found companies were clearer regarding whether payments were financial or benefits-in-kind, but transparency was particularly inadequate as to whether it could be determined if payments were indirect or direct and restricted or unrestricted, and almost no companies mentioned the VAT status of payments. Our findings suggest that the industry's self-regulatory approach to transparency has not been working efficiently. We suggest ways for standardising and increasing the precision of information by pharmaceutical companies and advocate for the introduction of a centralised, and easily accessible national-level payment database.

Keywords: patient organisations; pharmaceutical industry; disclosure; transparency

1. Introduction

Patient organisations' input is regularly sought by public authorities that license, appraise and price drugs in many EU countries for their unique insights on how patients view the risks and benefits of particular medicines (Culyer, 2005; EMA, 2018; NICE, 2018a). Furthermore, patient organisations increasingly contribute towards key aspects of pharmaceutical research including study designs and safety monitoring (European Patients Forum, 2013; Wehling et al., 2014). Given their growing policy and research involvement, patient organisations encounter many challenges in developing their capacity and expertise (Baggott and Foster, 2008; Löfgren et al., 2011).

These challenges may be addressed by partnering with pharmaceutical companies to secure funding and other support. Industry organisations and organisations closely aligned with industry have argued that patient organisation-industry financial relationships facilitate the development and optimal administration of drugs (EFPIA, 2017; Haerry et al., 2018) and boost patient organisations' expertise (Parsons et al., 2015). However, others have cautioned that financial relationships often represent a conflict of interest (COI, Lo and Field, 2009) undermining the legitimacy of patient organisations in many jurisdictions, including the UK (Davis and Abraham, 2013), Australia (Fabbri et al., 2019; Löfgren, 2004), Finland (Hemminki et al., 2010), US (Kopp et al., 2018) and Canada (Lexchin, 2019). This COI may involve patient organisations promoting particular drugs (Colombo et al., 2012), some with unclear therapeutic benefits (Grey and Bolland, 2015), or may encourage self-censoring to maintain relationships with collaborating companies (Batt, 2014).

One response to these controversies has been via enhancing the transparency of financial relationships between the two sides. This is part of a global policy trend in which transparency, primarily understood as public disclosures, is applied to individuals' and organisations' ties to pharmaceutical companies (Fabbri et al., 2018; Grundy et al., 2018). Regulators in drug appraisals and approvals ordinarily ask their patient organisation consultees to disclose any COIs associated with funding sources (EMA, 2018; NICE, 2018b). Separately, patient organisations may disclose industry links online, although some fall short with this aspiration (Colombo et al., 2012; O'Donovon, 2007). Perhaps the most comprehensive disclosure initiative has been introduced by the European Federation of Pharmaceutical Industries and Associations (EFPIA), representing pharmaceutical companies operating in Europe, via its Patient Organisation Code of Practice (henceforth 'the EFPIA Code', EFPIA, 2011). Implemented through industry self-regulation, this initiative requires companies to disclose support to patient organisations in Europe from 2012 onwards. The transparency of these pharmaceutical industry disclosures has not yet been assessed.

We examine the assumption that disclosure equals transparency (EFPIA, 2017), where disclosure is the reporting of payments and transparency is the clarity of the reporting. Viewing transparency as a multidimensional construct (Schnackenberg and Tomlinson, 2014), we consider the disclosure of information (i.e. reporting of payments), its accuracy (i.e. reporting the correct recipients, not concealing payments) as well as its clarity (i.e. providing informative descriptions of the disclosed payments). These are pertinent considerations since the alleged efficacy of industry self-regulation for ensuring transparency often becomes an argument against the introduction of legally binding disclosure laws (EFPIA, 2017), despite consistent findings of the shortcomings associated with self-regulatory approaches (House of Commons Select Committee, 2005; Zetterqvis et al., 2015). Specifically, we evaluate the extent of pharmaceutical company compliance with the EFPIA

Code using nine indicators constructed based on the Code and payment disclosures published by 108 companies covering payments in the UK made between 2012 and 2016.

2. Policy background - Industry self-regulation of payment disclosures to patient organisations

Applicable to company payments to patient organisations, the EFPIA Code (2011) stipulates that companies must "make publicly available a list of patient organisations to which it provides financial support and/or significant indirect/non-financial support" accompanied by a description which is "sufficiently complete to enable the average reader to form an understanding of the significance of the support". The monetary value or non-monetary benefit of the payment must be stated, and the information must be "provided on a national or European level and should be updated at least once a year".

The Association of the British Pharmaceutical Industry (ABPI) Code of Practice (2012), incorporates the principles of EFPIA's Code, and because of the similarities between the relevant sections of the Codes, we subsume the ABPI Code under the higher-level EFPIA Code. Two specific features of the ABPI Code are firstly that companies may also provide their payment as a percentage of the recipient's income, and secondly it excludes payments to patient organisations from Disclosure UK (Ozieranski et al., 2019a; Pearcy, 2019), a publicly available database of payments made to healthcare professionals (Mulinari and Ozieranski, 2018) and organisations (Ozieranski et al., 2019b). Instead, payments to patient organisations are disclosed on each company's website.

3. Materials and Methods

The data examined in this study is part of a large database of pharmaceutical industry payments to patient organisations (Ozieranski et al., 2019a), with the variables examining the transparency of financial disclosures developed specifically for this study. We considered 108 companies abiding by the ABPI Code (53 were members of the ABPI and 55 were not, as of 2018), of which 66 published a disclosure report for payments made in at least one year between 2012-2016. We analysed 220 disclosure reports, covering 5232 payments made between 2012-2016, and extracted them into a single database, including recipient name, payment value, any payment description, and whether the payment as a percentage of the recipient's income is provided. We adjusted the values to their 2016 sterling equivalent. Two researchers coded payment descriptions, with differences resolved by agreement.

For 444 (87%) out of 508 identified patient organisations registered with any of the UK's charity regulators (the Charity Commission for England and Wales, the Office of the Scottish Charity Regulator, the Charity Commission for Northern Ireland), we collected additional data from their financial accounts including financial year end, whether drug companies were mentioned and, if so, what companies.

3.1. Constructing the indicators of transparency

We deduced three general indicators of transparency from the EFPIA Code (see Web Appendix 1 for their elaboration). These apply to transparency under disclosure (indicator 1.1), accuracy (1.2 and 2.1-2.3), and clarity (3.1-3.4).

1. Do companies disclose payments to patient organisations?

1.1. *Availability of disclosure reports*

The EFPIA Code requires companies to "make publicly available a list of patient organisations to which it provides financial support and/or significant indirect/non-financial support" and to update this information annually, therefore at least one disclosure report per company should be available if payments have been made. Importantly, companies are not required to keep reports on their websites for a specific number of years and earlier reports may simply have been removed.

1.2. Undisclosed payments

As an absence of disclosures may indicate a lack of payments rather than a failure to disclose, the Charity Regulator data was used to support or challenge this assumption by checking if companies were mentioned as supporters in charity accounts covering 2012-2016.

2. Are the appropriate payment recipients being reported?

We excluded payments when they did not meet certain criterion, which we termed inappropriate recipients, for reasons outlined below under three specific indicators (2.1-2.3).

2.1. Recipients adhering to EFPIA's definition of patient organisation

Companies are required by the EFPIA Code to "make publicly available a list of patient organisations" rather than various organisation types, an important matter for ensuring the clarity and coherence of information, and a key precondition of determining the total funding received by patient organisations (another EFPIA requirement). We used the number of disclosed payments that did not adhere to EFPIA's definition of patient organisations (EFPIA, 2011) as a transparency indicator as many of these payments should be disclosed in Disclosure UK (ABPI, 2017). Notably, two companies (Flynn Pharma and Santen UK) stated on their websites that their payments to patient organisations were in Disclosure UK for 2016, and three companies stated this for 2015 (Alliance, Flynn Pharma and Santen UK). These companies' payments were extracted from Disclosure UK; however, most were excluded from analysis due to not being to patient organisations.

2.2. Single organisations reported as recipients

If a single payment was reported with more than one recipient this was excluded if the amount received by each recipient was unclear.

2.3. Organisations based in the UK reported as recipients

Disclosure requirements reflect a national system administered by the ABPI, and therefore non-UK organisations should be reported separately. We identified locations through supplementary searches of organisations' websites.

3. Clarity of payment descriptions

The EFPIA Code requires companies to provide payment descriptions so the "average reader" can "understand" the nature of the support. The following three sub-headings outline our approach to coding the quality of the 4572 payment descriptions remaining following exclusions identified in indicators 2.1-2.3.

3.1. Number of words used in payment descriptions

We assumed that more words typically equates to more clarity and detail.

3.2. Clarity of payment form and goal

We used payment descriptions to establish whether payment forms and goals were stated clearly. We defined payment form as the broad mode of the payment in terms of the capacity in which it was provided; payment goal was the intended use of the payment.

3.3. Clarity of payment descriptions using 5 sub-indictors

Using payment descriptions, we identified 5 sub-indicators of transparency which measure more specific payment details. As with indicator 3.2., these sub-indicators were deduced from the general requirements set out in the EFPIA Code (examples in Appendix 2). Namely, we determined whether each description provided enough information to identify if the payment is:

a) Core or specific
b) Financial or benefit in kind
c) Direct or indirect
d) Restricted or unrestricted
e) Inclusive or exclusive of VAT

Iterative readings of the payment descriptions with supplementary key word searches were conducted to code transparency indicators.

3.4. Payment as a percentage of the recipient's total income

Appearing only in the ABPI Code (2012), companies can, but are not obliged to, provide an "indication" of their support as a "percentage of the patient organisation's total income". This information indicates how the payment compares to the recipient's income.

3.2. Analysis

We conducted all descriptive analyses in Excel, with the exception of a Mann-Whitney U Test, which was conducted in SPSS to test the relationship between the number of words in a payment description and the clarity of the payment form and goal.

4. Results

We present our findings by reporting on the specific indicators under each transparency indicator category – (1) disclosure availability, (2) frequency of inappropriate recipients, (3) clarity of payment descriptions – and an assessment of the most/least transparent years.

4.1. How many disclosure reports were available?

Overall, 42 (38.9%) companies did not disclose payments to patient organisations on their website, whilst 12 companies (11.1%) disclosed payments for one year, 8 (7.4%) for two years, 13 (12.0%) for three years, 12 (11.1%) for four years, and 21 (19.4%) for all five years. Disclosure availability for payments made in 2016 was 42.6% of companies, but companies most frequently had a disclosure report available for 2015 (50%). Report availability was lowest for 2012 (27.8%), increasing slightly for 2013 (39.8%) and 2014 (43.5%) (see Appendix 3 for further details). Of the companies with at least one disclosure report available, 43 (65.2%) were ABPI members (as of 2018) and 23 (34.8%) were not. Conversely, of the companies with no disclosure reports available, 11 (26.2%) were ABPI members and 31 (73.8%) were not.

[Table 1]

The annual accounts of 444 (87.0%) patient organisations registered as charities revealed 23 (54.8%) companies with no disclosures available were mentioned on at least one charity account covering 2012-2016, with Genzyme being named most frequently (37 accounts), followed by Sigma Tau Rare Disease (8 accounts) and PTC Therapeutics (6 accounts) (Table 1). The figures for Genzyme exclude accounts covering 2016 as Sanofi disclosed its subsidiary Genzyme's payments for that year (but not 2012-2015). Companies with no disclosure reports were mentioned in 10 charities' accounts in 2012, 11 in 2013, 14 in 2014, 13 in 2015 and 17 in 2016 (figures exclude Genzyme). Of the companies mentioned in charity accounts, 5 (21.7%) were ABPI members and 18 (78.3%) were not, whilst for companies not mentioned in charity accounts, 6 (31.6%) were ABPI members and 13 (68.4%) were not.

4.2. What other recipients were disclosed as patient organisations?

In total 656 (12.5%) of all disclosed payments had an inappropriate recipient. Eighteen companies dominated the picture with 20% or more (up to 100%) of their payments disclosed inappropriately, whilst in contrast 18 companies did not disclose any payments inappropriately (see Appendix 4 for details for each company). Companies reported a high volume of payments to organisations that did not adhere to EFPIA's definition of a patient organisation (528, 10.1%). Some organisation names were also ambiguous and therefore could not be identified (57, 1.1%). Other inappropriate recipients were those not operating in the UK (54, 1.0%), and, occurring least frequently, more than one organisation reported for a single payment (17, 0.3%). Over 2012-2016 there were no clear changes over time, although the percentage of recipients that were not patient organisations was lowest in 2013, 2014 and 2015 (9.3%, 9.6%, 8.0%, respectively) than in 2012 (17%) and 2016 (13.8%) (annual overview in Appendix 5).

4.3. How informative were payment descriptions?

The majority (3013, 66.0%) of disclosed payments were accompanied by a description of between 1-20 words (Table 2). Just 25 (0.6%) of payments had no description or details at all, with low percentages also being observed in the payments with the most words (51+). The most frequent length for a description was between 1-10 words with a median payment value of £5,050. The median value of payments did not increase beyond £5,050 until the number of words reached 61+ (examples of descriptions lengths in Appendix 6).

[Table 2]

As Table 2 demonstrates, longer descriptions of between 61-183 words were associated with higher median values (from £6,307.45 for 71-80 words to £14,140.00 for 91-100 words) and interquartile ranges (from 894.53 for 61-70 words to £17,753.11 for 81-90 words) than the shorter descriptions. Of the 110 payments that had longer descriptions, only 8 were describing more than one distinct payment goal, leaving us to tentatively conclude larger payments are associated with longer descriptions. Grouping description lengths into short (0-20), medium (21-50) and long (51+), displayed no clear changes over time, for example the number of short descriptions was similar in 2012 and 2016 (66.7% and 64%, respectively) (see Appendices 7 and 8).

The value of payments with unclear payment goals was £3,508,568.12 (6.1%) out of £57,305,252.78. Descriptions with unclear payment forms were a higher value of £4,817,512.52 (8.4%), whilst descriptions with an unclear form and goal were valued at £753,597.86 (1.3%). Table 3 reports the percentage (of the number of payments) of descriptions with an unclear payment form (7.4% of total) and goal (7.6% of total) out of 4572. The proportion of descriptions with unclear payment forms and goals was lowest in 2016 (52, 4.5% and 70, 6.1%, respectively), and highest in 2014 for payment goal (78, 9.0%) and in 2015 for payment form (95, 9.6%). Appendix 6 provides example descriptions within the various wordcount brackets, accompanied by our coding of the payment form and goal (both clear and unclear). A Mann-Whitney U test indicated that the number of words used to describe payments with clear payment forms was higher than unclear ($U = 428416$, $p = .000$). The same applied to clarity of payment goals ($U = 155399$, $p = .000$). Payment descriptions of >50 words had no unclear goals, whereas all but two wordcount brackets (61-70 and 71-80) contained unclear payment forms. Fourteen companies did not make the goal of their payment clear in 20% or more of their payments, within which three companies had no descriptions with clear payment goals (Appendix 9).

[Table 3]

Descriptions were clear as to whether they were financial or a benefit in kind (35, 0.8% were unclear) but a higher number of payments were unclear as to whether the payment was for general core funding or if it was for a specific activity (470, 10.3%). Many descriptions did not clearly state whether payments were indirect or direct (3775, 82.6%) and were even more unclear regarding whether payments were restricted or unrestricted (4376, 95.7%). Similarly, the majority did not mention the VAT status of the payment (4543, 99.4%). Overall, there were no obvious changes over the five years (Table 4), although the number of payments that were unclear regarding restricted or unrestricted decreased consistently between 2012 (99.1%) through to 2016 (91.2%).

[Table 4]

Continuing this trend, the percentage of the recipient's funding represented by each payment was only provided by 1 company (of 30, 3.3%) in 2012 (Pfizer), 1 (of 43, 2.3%) in 2013 (Pfizer), 1 (of 47, 2.1%) in 2014 (Pfizer), 1 (of 54, 1.9%) in 2015 (Pfizer), and 3 (of 46, 6.5%) in 2016 (Chugai, GSK, Pfizer).

4.4. Overview: least and most transparent years

Although there were very few noticeable changes over time, collating all of the indicators applying to inappropriate recipients (indicator 2) and clarity of payment descriptions (indicator 3), 2016 comes out as the most transparent year (top on 8 of 13 indicators) and 2012 as the least transparent (bottom on 5 of the 13 indicators), as displayed in Appendix 10.

5. Discussion

Unlike transparency studies of patient organisations' reporting of relations with the pharmaceutical industry (Colombo et al., 2012; Jones, 2008), ours is the first analysis evaluating the industry's self-regulatory approach to transparency. We found that many companies lacked available disclosure reports, despite many of these being found to have made payments. Where disclosures were available, different recipient types were sometimes mixed together, with varying levels of information provided. These transparency shortcomings, coupled with the implications that pharmaceutical funding of patient organisations can have on health policy (Batt, 2017), raise questions about the sufficiency of the self-regulatory approach to payment disclosures. These concerns coincide with the shortcomings of industry self-regulation relating to the disclosure of payments to UK healthcare professionals (Mulinari and Ozieranski, 2018) and organisations (Ozieranski et al., 2019b).

5.1. Compromised transparency through withholding payments

The EFPIA Code requires companies to annually update the list of supported organisations. Therefore, unless companies delete their reports or make no payments, at least one disclosure report should be available on every company website. Disclosure reports were available more frequently for companies that are ABPI members (65.2%) than not (34.8%), indicating membership of ABPI equates to greater transparency. Over half of the companies with no disclosure reports were mentioned in at least one charity annual account, suggesting failure to disclose, which is particularly worrying given that discrepancies with charity accounts occurred primarily towards the end of the period of observation (2015-2016) meaning they are unlikely to have been removed.

The majority (73.5%) of companies with no disclosure that were mentioned in charity accounts were not ABPI members. This suggests that ABPI members are less likely to have undisclosed payments than non-members. Still, ABPI members are expected to abide by the standards set out by the ABPI Code (which we subsume under the higher-level EFPIA Code), therefore all ABPI members that have made payments should have a report available, unless they made no payments or payment reports have been removed. Disclosure UK requires companies to maintain disclosure information in the public for three years (ABPI, 2016), therefore one might assume a similar timeframe for patient organisations. It is positive that 34.8% of non-members had a report available, as it reflects voluntary abidance of the relevant Codes.

There is also a question mark over the remaining 19 companies with no disclosure reports available, and which were not mentioned in charity accounts, as we only looked at patient organisations in our sample which were registered with a charity regulator (444 of 508) and relied on patient organisations being transparent about their funders, although research has found that this is not always the case (Colombo et al., 2012).

5.2. Inappropriate recipients: confused or careful?

Inappropriate recipients artificially inflate the number of and value of payments. The high number of payments disclosed to recipients that we identified as not adhering to EFPIA's definition of patient organisation (528) may reflect companies misinterpreting the definition of patient organisations, a well-known difficulty (Nicholas and Broadbent, 2015), which may lead some companies to over-disclose rather than potentially withhold payment information. It may also indicate the complexity of collaborative arrangements involving a patient organisation not receiving funding. Furthermore, three companies stated they disclosed payments to patient organisations in Disclosure UK, a separate disclosure system for healthcare organisations (Ozieranski et al., 2019b). This heavily complicates matters as Disclosure UK does not differentiate between payments to different organisation types (Ozieranski et al., 2019b), thus necessitating supplementary web searches to determine the level of support to patient organisations. Similarly, payments are not described beyond four generic payment categories, thus companies disclosing in Disclosure UK fall short of the EFPIA Code's minimum transparency requirements.

5.3. Form and goal of payments: murky descriptions or adequate information?

Although unclear payment descriptions did not exceed 9.6% for either payment form (nature of the payment, such as sponsorship or a grant) or goal (reason for the payment, such as for policy engagement or education and training), their value was substantial at £4,817,512.52 and £3,508,568.12, respectively. Therefore, the average reader will not know how a large chunk of payments were made or what purposes they were intended to support. We identified a link between the number of words used to describe payments and whether payments' form and goal could be identified, thus validating our assumption that more words meant improved understandability. Conversely, shorter descriptions are making it unclear what large proportions of money are used to pay for, in apparent violation of the EFPIA Code.

5.4. Blurry picture of transparency for clarity of descriptions

Most descriptions were clear regarding whether payments were financial in nature or a benefit in kind. Yet the transparency picture was blurred when determining whether payments were provided for core or specific purposes, suggesting that companies were not always transparent as to whether their payments were intended for covering administrative costs, or specific purposes, such as sponsoring an event. Because industry funding represents a potential for a conflict of interest or a loss of independence (Ball et al., 2006), it is concerning that this information was not provided systematically. Further, despite an improvement between 2012-2016 (from 99.1% unclear to 91.2%) the majority of descriptions were unclear as to whether the payment was restricted or unrestricted. This makes it difficult to determine whether payments were made with specific requirements or conditions, or if the payments were flexible in terms of access and use.

The picture became dramatically blurrier under the sub-indicator categories 'indirect or direct', 'restricted or unrestricted' and whether VAT is mentioned. Being able to identify whether payments were made directly or indirectly is an important distinction (ABPI, 2016) and helps the reader determine the ultimate financial beneficiary. This is important as making payments via a third party might allow for hiding money (Steinbrook and Ross., 2012). For example, if a company pays a PR firm to assist a patient organisation but the patient organisation is not reported as the ultimate recipient, there is a serious transparency shortcoming. It is also problematic that companies are not transparent about whether payments include VAT as this makes it difficult to determine whether the payment value disclosed is the payment amount received in full by the recipient (Ozieranski et al., 2019b; RAND, 2016). Overall, the very high (80% or more unclear) failure to report on three of the five clarity sub-indicators may be indicative of the EFPIA Code not stipulating clearly enough the need for additional information of this nature about payments.

Important information is being neglected as very few companies provided their payment as a percentage of each recipient's total income (the highest was 3 companies in 2016). The provision of this additional clarity would allow the reader to develop an understanding of the size of a payment in relation to the recipient size, as well as keep a track on patient organisations' dependency on industry funding (Kent, 2007), which may lead to questions around undue influence (EFPIA, 2017).

5.5. Scattered improvements over time

Improvements over time were scarce across most of our transparency indicators. Although it is promising that disclosures covering 2016's payments were the most transparent, marked improvements were only observed in the clarity of whether a payment was restricted or unrestricted (improved by 7.9%) and the proportion of payments with unclear payment forms, which more than halved.

6. Possible policy solutions

Our findings suggest that all companies should publish a disclosure report annually (regardless of whether they made any payments) using a standardised template which includes fields such as recipient, value of support, VAT status of value, goal of support, amongst other important variables highlighted in our paper. Until a recent update to the EFPIA Code (2019) it was unclear how long companies were expected to keep disclosure reports publicly available for. The Code (2019) now states that disclosure reports must be publicly available for at least 3 years, although this provision does not extend to the ABPI Code (2019), which still neglects this important point. This would allow policymakers, researchers and patients access to a precise overview of company payments in terms of their value and impact, in particular to determine the level of control a company has over the money. A specific definition of a patient organisation would address the current overlap between the nominally separate disclosure systems for healthcare organisations (Disclosure UK) and patient organisations (disclosures on individual company websites).

Preferably, under the auspices of the ABPI, disclosure reports should form a central, annually updated database similar to Disclosure UK, while eliminating its well-recognised shortcomings (Mulinari and Ozieranski, 2018; Ozieranski et al, 2019b). Systematic oversight of regulations is also critical as companies providing funding to patient organisations focused

on conditions for which they produce medicines (Lexchin, 2019; Mandeville et al., 2019). Therefore, the ABPI must monitor the compliance of disclosures with its Code, and by extension the EFPIA Code, to enable patients, carers, and policy-makers to make informed decisions about the information provided by patient organisations. Although increased transparency may not resolve potential conflicts of interests (Cain et al., 2005; Kmietowicz, 2016), it is vital for good pharmaceutical governance (Kohler et al., 2016).

7. Limitations

The limitations of our research lie, firstly, in difficulties associated with the interpretation of the absence of many disclosure reports. Although we compared companies with no disclosures with charity annual accounts, we only based this on patient organisations that had been reported in another company's disclosure. We also cannot be certain if companies previously had disclosure reports available but removed them. Crucially, charity accounts are not always transparent either. These limitations have likely resulted in us underestimating the value of undisclosed payments.

Secondly, whilst we deduced what we could from the EFPIA Code, our transparency indicators are not exhaustive and may be open to interpretation.

Thirdly, the quantitative nature of our research is as a limitation, particularly with regard to relying on the number of words used to describe payments as a transparency indicator, as well as reducing potentially rich data into quantitative codes.

8. Conclusions

In the UK, the pharmaceutical industry's self-regulatory approach to transparency (considered multi-dimensionally, encompassing disclosure, accuracy, and clarity) of financial relations with patient organisations has not been working efficiently, and it is likely that many of these issues extend across Europe. With such complex relations as pharma-patient organisation ties, closer regulatory monitoring and standardisation in a centralised disclosure system is needed to enhance transparency and make these ties more accessible and comparable across companies and patient organisations.

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